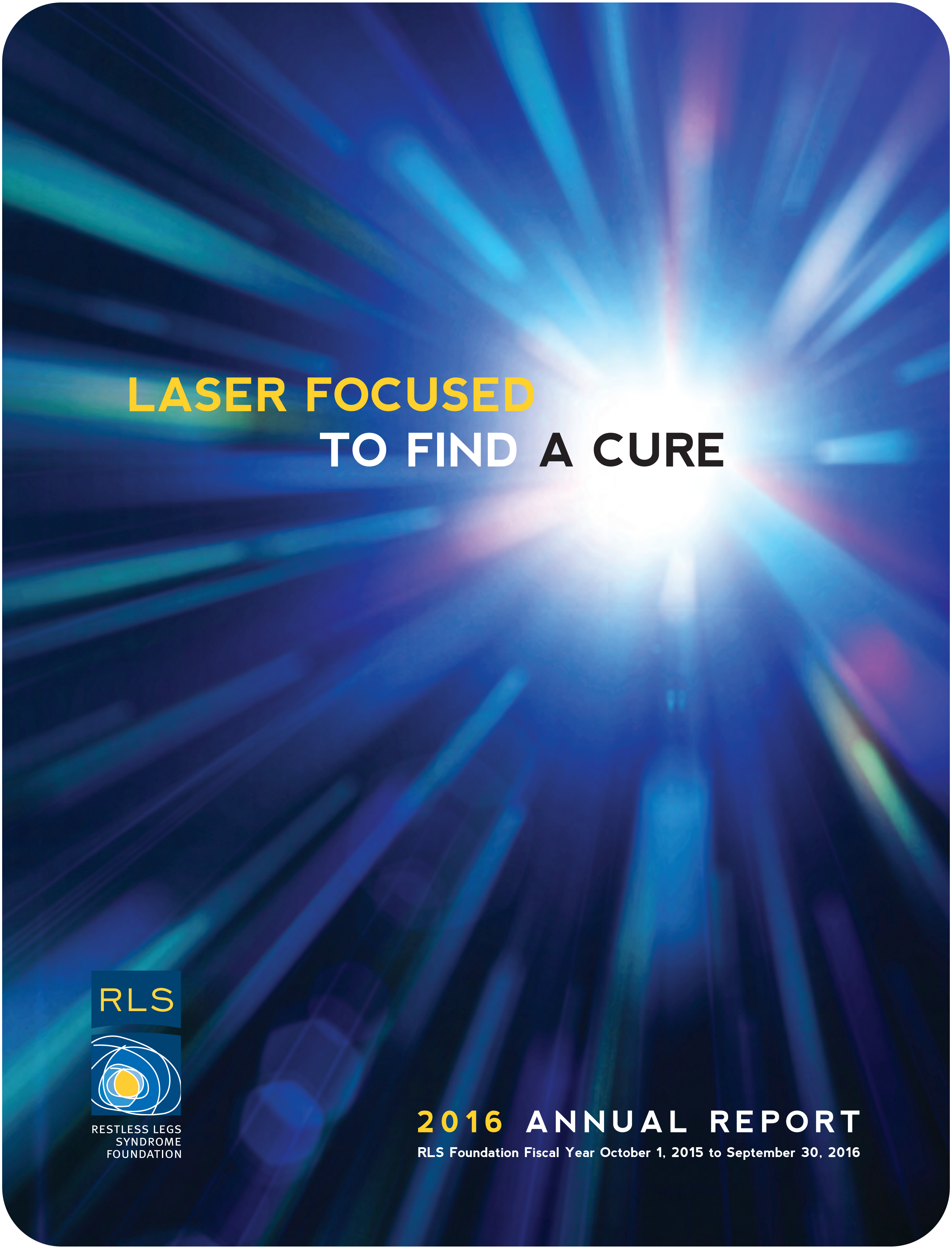


LASER FOCUSED TO FIND A CURE

RLS
RESTLESS LEGS
SYNDROME
FOUNDATION

2016 ANNUAL REPORT

RLS Foundation Fiscal Year October 1, 2015 to September 30, 2016

Restless Legs Syndrome Foundation, Inc. is dedicated to improving the lives of the men, women and children who live with this often devastating disease. The organization's goals are to increase awareness, to improve treatments and, through research, to find a cure for RLS.

Board of Directors

2016 RLS Foundation Scientific and Medical Advisory Board

The Restless Legs Syndrome Foundation Board of Directors held meetings on:

November 6–8, 2015
Annual Meeting

December 11, 2015
Telephonic Meeting

March 3, 2016
Telephonic Meeting

July 19, 2016
Telephonic Meeting

September 23–25, 2016
Annual Meeting

2016 Highlights I From the Chairman of the Board

Lewis Phelps
Chair, RLS Foundation
Board of Directors

The last year has been dramatic and pivotal in the 25-year history of the RLS Foundation.

We have much of which to be proud. After a steep decline in funding from pharmaceutical companies in recent years, we have rebuilt a strong financial foundation through a systematic fundraising campaign reaching out to new audiences affected by the disease. This campaign has drawn thousands of new members and supporters to work together in finding treatments and a cure for RLS.

Based on our renewed financial strength and management of the Foundation that is focused on efficient use of our donors' gifts, we have assembled an extraordinarily capable, dedicated team of employees at our headquarters in Austin, Texas. Your support has enabled us to plan on tripling the funding we provide for researchers. We have established a new combined Scientific and Medical Advisory Board to recruit outstanding researchers who will focus on the complexity of RLS issues in their work, provide guidance to them, and help move new medications quickly from the research bench into the hands of physicians who treat patients with RLS.

We also are blessed to have a dedicated group of volunteers who serve on our Board of Directors, several specialized committees, the Scientific and Medical Advisory Board, and as leaders of dozens of Support Groups around the country.

Underlying every success over the past year has been the willingness of each of you who have donated money to help keep the good work of the organization going forward and to fund greater research. From individuals who support us with their annual membership fee to generous individuals and foundations who commit major gifts, it all makes a difference. To each supporter, Thank You! From the bottom of my heart, Thank You!

As happy as I am about what the RLS Foundation has achieved in the last year, I look ahead at how much remains yet to be done. Our challenges include grappling with the growing threat of restrictions on use of low dose opioids to treat refractory cases of RLS, finding new and durable treatments for this disease, finding its cause so that we can create a cure, and educating healthcare providers as well as a wide swath of the American public about the immeasurable damage to quality of life caused by restless legs syndrome.

The challenges are great, but so are our opportunities. We just have to keep striving. As Benjamin Franklin said, "There will be sleeping enough in the grave."

Lew Phelps
Chair, RLS Foundation Board of Directors

RLS Foundation Launches Reinvigorated Research Grant Program

By Lewis Phelps, Chair, RLS Foundation Board of Directors

As newly elected chair of the RLS Foundation Board of Directors, I want to report on some exciting and significant changes adopted unanimously by the Board at a recent meeting in our headquarters city of Austin, Texas.

We have set forth a reinvigorated strategy for the RLS Foundation Research Grant Program that will drive RLS research forward rather than waiting for opportunities to be presented to us. The Board has committed the Foundation to a significantly higher level of annual funding in support of research – both basic and clinical – to get to the root of this disease, develop treatments and find a cure. The RLS Foundation will provide at least $200,000 in research pilot grants in 2016 (almost triple our historical average) and up to eight research projects (versus one to three previously).

Our goal is simple: we want to find a cure for this loathsome disease. By multiplying our commitment to research funding, we hope to accelerate that outcome.

The reinvigorated strategy for the Research Grant Program includes:

- Identify potential research projects and reaching out to researchers who could help move us toward our goal of eradicating RLS
- Increase research funding to $200,000 annually for up to eight pilot grants, through additional donations to the Research Grant Program from individual donors
- Review and approve grants on a continual basis, rather than just once a year, using the same rigorous review process currently used to evaluate grant proposals
- Provide counsel to RLS Foundation grant seekers to improve the strength and outcomes of their research studies
- Identify potential sources of later-stage funding (from the National Institutes of Health (NIH), for example) for research that the Foundation has sponsored in initial phases
- Expand our reach to biotech and medical technology companies as collaborators that can help us achieve progress toward a cure
- Fund a study of the health burden of RLS – the direct yearly cost of caring for people with the problem and the indirect cost of lost time and work – for leverage when lobbying the NIH and Department of Defense to step up governmental funding for RLS research


Lewis Phelps

In addition, we aim to have a significant presence at professional scientific meetings. As a first step, we will have a booth in the exhibition area of the Society for Neuroscience annual meeting (November 12–15 in San Diego). For that event we have proposed a symposium on RLS featuring leading basic and clinical researchers.

The Board's strategic planning discussions leading to these changes made it clear that our existing structure of separate Medical and Scientific Advisory Boards is not the best way to manage an expanded, accelerated research process.

The Board agreed to create a wholly new entity – the RLS Foundation Scientific and Medical Advisory Board – to bring together, in a single body, talent from the spectrum of institutions and disciplines that may advance our mission. Issues such as healthcare economics, public health policy, and epidemiology may well inform the new Advisory Board's agenda.

We will use the pool of expertise we're assembling on the new Advisory Board to provide assistance in all elements of our reinvigorated research grant program, including the identification of potential donors to support our amplified funding effort. We will announce our new roster of Advisory Board members soon and hope to include members from the world of biotech and medical technology companies, as well as large and small pharmaceutical businesses.

The RLS Foundation has always had three major goals: to raise awareness and educate people about the disease, improve treatments, and through research, find a cure for RLS. Without diminishing our commitment to the first two goals, our new research initiative greatly increases our ability to find a cure.

Your generous financial support is more crucial than ever. Please join us in making it possible to find a cure.

To make a donation to the RLS Foundation Research Grant Program, visit www.rls.org or call 512-366-9109.

Research on RLS: How We Are Tackling This Complex Challenge

By Michael J. Zigmond, PhD, and Beth A. Fischer, PhD

Restless legs syndrome (RLS) affects at least 7 to 8 percent of the worldwide population and, as readers of *NightWalkers* know all too well, it can be a devastating condition. Although it was first described almost 350 years ago, we still do not know enough about its cause to develop sufficiently effective treatments, let alone to provide a cure. These objectives are impeded by a critical lack of knowledge, which must come from a combination of basic, translational and clinical research.

Basic research can provide us with a better understanding of the cellular and molecular processes that occur within the brain areas thought to be responsible for the symptoms of RLS, as well as the reasons that traditional drug treatments so often lead to augmentation – an actual worsening of the symptoms over time. *Translational research* applies that knowledge to examine how we might intervene to treat the disorder in realistic animal models of RLS. And *clinical research* is needed before any prospective treatment can be approved for human use.

How does a researcher go about tackling the complex problem of developing treatments for a clinical disorder such as RLS?

First, the researcher must learn what is already known. This involves reading scientific papers and talking to other researchers in the field, often at scientific meetings or during visits to other laboratories. The latter step is critically important, as published research may be as much as two years behind what is currently being done in the lab.

Second, a researcher must develop a hypothesis (theory) concerning the cause or treatment of the condition.

Third, he or she must develop an approach for testing that hypothesis. This usually involves having the necessary space, methods, equipment and staff. Often it also involves assembling a team that includes collaborators at other institutions, including both universities and private institutions such as biotech companies.

Fourth, the researcher needs money. The researcher will start with a small pilot study to see if a hypothesis is feasible or to obtain preliminary data validating the research methods. This might cost $50,000 or $100,000. Currently, the RLS Foundation is the only organization set up to consider such grants. And those funds are just for a preliminary study; full-scale basic or translational studies can easily cost $250,000 a year or more for up to five years – and clinical studies cost much more.

Fifth, the research must be completed, the data carefully analyzed, and the paper written and published so that others can join in the task at hand.

Michael J. Zigmond, PhD

Beth A. Fischer, PhD

There are quite a few researchers who could be investigating RLS. They have the necessary expertise, space, methods, equipment and staff. What most lack, however, is an awareness of the disease and the money needed to conduct the research.

The RLS Foundation recognizes these issues as barriers to advancement and has launched a reinvigorated strategy for the Research Grant Program (see page 3) that will impact the research effort in important ways:

1. The strategy includes a stepped-up program to educate researchers about RLS and the urgent need for more research. The Foundation will actively seek out investigators with potential to work on the problems and encourage them to pursue paths that may lead to new treatments.
2. The strategy greatly expands the Foundation's pilot grants for research on RLS. Currently, most funding for biomedical research in the U.S. is provided by federal agencies such as the National Institutes of Health (NIH). To get those large grants, pilot data showing support for an idea is essential. Thus, pilot grants from the RLS Foundation not only promote research on the disorder, but also position researchers to attract even more funding for RLS from other sources.

You can help, too. You can make an extra contribution to the RLS Foundation Research Grant Program this year. And you can write to your legislators urging them to increase funding for the research that will ultimately alleviate the suffering that RLS causes to so many.

About Michael Zigmond and Beth Fischer

Michael Zigmond is a researcher in neuroscience and a member of the RLS Foundation Board of Directors; Beth Fischer is an educator and a person living with RLS. Both can be found at the University of Pittsburgh.

Study Finds More White Matter Lesions in Patients with Late-Onset versus Early-Onset RLS

The 2015 RLS/WED Science Summit was an exciting gathering of scientists who have a passion for understanding why RLS happens and how we might be able to improve future treatment, and who share a common goal of working toward an RLS cure. In the highlights below, I discuss some of the science presented in the meeting. Due to space limitations, and the impressive breadth and depth of RLS research presented at the three-day summit, not all aspects of ongoing RLS research can be covered here.

What Causes RLS?

A key question in our understanding of RLS revolves around what causes this disease to occur. A number of different lines of exploration are ongoing, focusing on dopamine, brain iron deficiency, spinal cord functioning, the opiate (pain-relieving) system and genetics.

Considering the latter, RLS has long been known to run in families and have a genetic predisposition, but our understanding of the specific genes at play in the development of RLS has only recently expanded in the last decade. Starting in 2007, genome-wide association studies have identified six different genetic regions that contain variants within single nucleotides (adenine (A), cytosine (C), thymine (T) and guanine (G) – the building blocks of DNA) that tend to be different between people who have RLS and controls without RLS. None of these six genetic regions by themselves account for all RLS, but each individual's combination of gene variants helps to determine whether or not a person will develop RLS (with some environmental influences also at work).

When the six genetic regions were initially found to be associated with RLS, the ways in which they might cause RLS were not at all clear. However, these regions (or very closely related genes) are also present in many animals. Their presence has allowed RLS researchers to take what is known about human RLS genetics and use it to develop animal models of RLS.

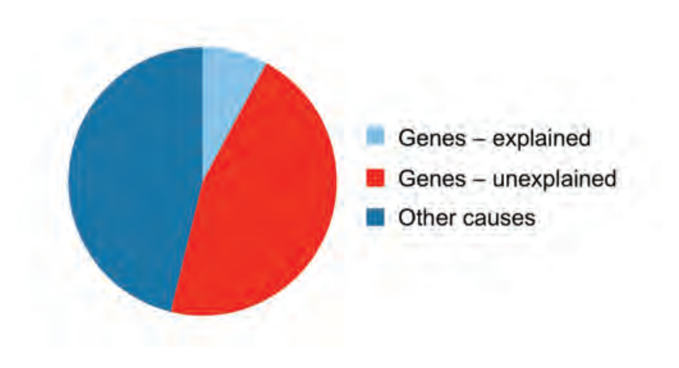
Some of the genes identified in humans have now been manipulated in flies, worms and mice. Specifically, scientists have manipulated the gene BTBD9 in rodents and flies, PTPRD in flies, and MEIS1 in worms and rodents. Of course, these animals cannot describe urges to move their legs at night, but careful studies of affected animal behavior versus unaffected animal behavior demonstrates differences in motor activity, reactions to sensory stimuli, and rest/sleep patterns, all of which are reminiscent of RLS in humans. (For an example, see "Using BTBD9 to Simulate RLS in Fruit Flies" on page 9.)

These animal models not only have been helpful in providing evidence that the genes have a causal relationship to RLS, but also have provided investigators with models that will allow more detailed investigations of how the genes interact with other systems that have been implicated in RLS. Animal models, whether genetic or otherwise (for example, animal models of iron deficiency), may also prove useful in RLS drug development in the future.

Lynn Marie Trotti, MD, MSc

While these advances in RLS genetics are undeniably helpful, it is also clear that the six identified regions do not explain all, or even nearly all, of the genetic contribution of RLS. Other genetic variants, rare or common, await identification to enhance our understanding of RLS. (See "How much of RLS does this explain?" below.)

How Much of RLS Does This Explain?



Please note: *This pie chart is an estimate for the purpose of illustration, not a precise comparison.*

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Relationship with Cardiovascular Disease

One of the most pressing clinical questions about RLS is how it is associated with cardiovascular disease such as heart disease, stroke and high blood pressure.

Multiple studies have evaluated for associations between cardiovascular disease and RLS or periodic limb movements of sleep (PLMS). The results of these studies have been mixed, with many suggesting a relationship between having RLS (or PLMS) and having cardiovascular disease, but some other large, carefully controlled studies suggest that there is no such relationship. Separate from studies that address the relationship at one point in time, studies designed to assess RLS (or PLMS) at an initial time point and then the subsequent development of cardiovascular disease at a later point have also been completed, but have had similarly mixed results.

Some studies have even suggested that having multiple diseases (including cardiovascular disease), so-called *multimorbidity*, might predict RLS. While epidemiologic studies such as these can be helpful in identifying potential relationships, they cannot truly resolve questions of cause and effect. Studies that are more mechanistic are needed – that is, those looking at potential ways whereby RLS or PLMS could cause cardiovascular disease (or the opposite) – to more firmly establish biological plausibility for such an effect.

In sleep apnea, another sleep disorder that disrupts nighttime sleep, there is a more firmly established link between apnea and cardiovascular disease. The relationship between apnea and cardiovascular disease is thought to be mediated by several different mechanisms, some of which theoretically could be present in people with RLS. These include: low oxygen (not present in RLS); changes in pressure in the chest (not present in RLS); impaired function of blood vessels, especially the endothelial lining (unknown in RLS patients, but known to be affected by sleep deprivation); stiffness of the aorta (unknown in RLS patients, but known to be affected by sleep deprivation); abnormal stress hormone system activation (possibly affected in RLS; sometimes implicated in obstructive sleep apnea (OSA)); and abnormal regulation of blood pressure-related hormones renin and angiotensin (unknown in RLS; impaired in sleep deprivation and possibly in OSA).

Much interest exists in evaluating these mechanisms in RLS patients to help untangle the relationship between RLS and cardiovascular disease. Importantly, at this point in time we do not know if treating RLS or PLMS has an impact on long-term risk of cardiovascular disease, and treatment decisions are still individualized based on symptoms.

Treatment of RLS

Treatment decisions for RLS are supported by a number of well-performed, large, randomized, placebo-controlled trials; that is, we have a number of treatments that we know are effective for RLS. However, deciding between different treatment options can pose more of a challenge, because trials directly comparing two medications (rather than comparing one medication to a placebo) are less commonly performed.

This being said, a recent study by Richard P. Allen, PhD, and colleagues (published in *The New England Journal of Medicine* in 2014) compared two commonly used treatments, pramipexole (a dopamine agonist) and pregabalin (an alpha-2-delta ligand, not approved by the U.S. Food and Drug Administration (FDA) for the treatment of RLS). Both medications worked well to control symptoms. However, augmentation (the worsening of RLS symptoms provoked by medication) was less common with pregabalin. This has led to the suggestion by the International Restless Legs Syndrome Study Group (IRLSSG) that alpha-2-delta ligands (gabapentin, gabapentin enacarbil and pregabalin) be considered as first-line treatment for RLS when possible, but with the caveat that because the two classes of medications have quite different side effects, treatment must still be individualized. Gabapentin enacarbil (Horizant) is the only alpha-2-delta ligand that is FDA approved for the treatment of RLS.

[See *Guidelines for the first-line treatment of restless legs syndrome/Willis-Ekbom disease, prevention and treatment of dopaminergic augmentation: a combined task force of the IRLSSG, EURLSSG, and the RLS-foundation* on www.ncbi.nlm.nih.gov/pubmed/27448465]

Intravenous iron may also be considered in the treatment of RLS, especially in patients with low blood levels of iron who cannot take or do not respond to oral iron replacement. Placebo-controlled studies of intravenous iron have been performed using two different kinds of iron, one that was shown to be helpful (ferric carboxymaltose) and one that was shown not to be helpful (iron sucrose). RLS researchers have proposed that this difference reflects two factors: 1) iron sucrose has a shorter half-life, meaning it may be less available during the time the brain is absorbing iron; and 2) macrophages (cells involved in the process of getting iron into the brain tissues that need it) appear to react

continued on page 8

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differently to iron sucrose than to ferric carboxymaltose. Therefore, use of intravenous iron may not be sufficient; a particular formulation of iron may be needed for RLS patients using this kind of therapy.

Steps Toward Better RLS Treatments

It is always a long road from finding a scientific discovery to advancing it into clinical practice, but basic science is the first step. It is encouraging to see all of the RLS research underway and people in the scientific community who are working to understand RLS. Our hope is that we will someday be able to translate what we are learning through basic science into treatments that will help improve quality of life for people with RLS.

Using BTBD9 to Simulate RLS in Fruit Flies

A number of research teams are using genetic manipulation to develop animal models of RLS. While animals can't describe RLS-like sensations in their limbs, researchers can observe movements. In one example, scientists genetically manipulated the BTBD9 gene in *drosophila* (fruit flies) and tracked how the flies moved over time. The normal flies moved back and forth somewhat, but those with the BTBD9 gene manipulated to simulate RLS moved around a lot more, in a nonlinear way (Freeman, A, *Current Biology*, 2012).

About Lynn Marie Trotti

Lynn Marie Trotti, MD, MSc, is an associate professor of neurology at Emory Sleep Center, Emory University School of Medicine. Dr. Trotti is an RLS Foundation Advisory Board member and director of the Emory RLS Quality Care Center.

Foundation Funds Study on Cost-Effectiveness of RLS Treatment

The RLS Foundation has awarded a $36,750 grant to William Padula, an assistant professor at Johns Hopkins Bloomberg School of Public Health, for research to perform a cost-effectiveness analysis on treating patients with RLS.

This study is the first to provide a comprehensive evaluation of the cost of RLS treatment in the U.S. The analysis covers the period beginning when patients first seek medical help for RLS symptoms and includes costs related to loss of work and time, in addition to medical expenses.

In research that began in February 2016, Padula's team has conducted a systematic review of published studies on RLS misdiagnosis rates and found that RLS is misdiagnosed about 90 percent of the time, primarily as one of four conditions: Parkinson's disease (PD), sleep disorder, attention deficit hyperactivity disorder (ADHD) or depression.

> *"Medical care surrounding RLS is so poor right now – not because we have poor doctors, but because we don't train them."**

The researchers have created a structural decision model for treatment that captures the often multiple attempts to gain a proper diagnosis. For example, a patient who is misdiagnosed with ADHD may take medications that actually worsen RLS symptoms, and subsequently be misdiagnosed with PD. The period of misdiagnosis commonly persists for years, taking a significant toll on sleep and quality of life.

"If we invest money wisely in treating people, it improves either their quality of life or the duration of their life expectancy," says Padula. "We are trying to show that it does both, and that you get a lot of value out of the money spent in treating RLS."

Findings from the study will strengthen the case for increased physician training. "Medical care surrounding RLS is so poor right now – not because we have poor doctors, but because we don't train them," says Padula. "Doctors in primary care medicine are the gatekeepers referring patients to neurologists and need to be able to diagnose RLS correctly."

The study will report the cost of intervening to educate physicians, relative to quality-adjusted life years (QALYs), where one QALY equates to one year in perfect health added to an individual's lifespan as the result of this intervention.

William V. Padula, PhD

Preliminary results indicate it would be very cost-effective to increase physician education on RLS, according to Padula, especially if this training can be integrated into the existing training period of internal medicine residency. Data from the study will potentially be used to lobby for the American Medical Association to take such action.

Findings will also support the case for greater research funding from agencies such as the National Institutes of Health (NIH) and the United States Department of Defense (DOD).

"Investing something in this research now could make it more important on a national scale in the future. People will recognize it better, and the return on investment for addressing it," says Padula.

About William Padula

William V. Padula, PhD, is an assistant professor of health policy and management at the Johns Hopkins Bloomberg School of Public Health. His research explores problems in health economics and health services research with a focus on the theoretical foundations of medical cost-effectiveness analysis and the cost and quality improvement of hospital care.

* *Editor's note: This is factual. In medical school, doctors are not trained to recognize and treat RLS. Education and awareness continue to be two areas of focus for the RLS Foundation. To this end, the Foundation has executed an education and awareness program targeted at physicians practicing in primary care, pulmonary medicine, sleep medicine, and neurology through a direct-mail campaign of educational materials about RLS, as well as the prevention and treatment of augmentation.*

Managing Your Magnesium

By Norma G. Cuellar, PhD, RN, FAAN

Many persons with RLS ask about the use of magnesium (Mg) to help with symptoms. While research in this area is scant, magnesium can certainly affect other health conditions, thereby affecting RLS symptoms.

What is magnesium?

Magnesium is an element found throughout the body in blood, bones and soft tissues. Magnesium works with over 300 enzymes that regulate protein synthesis, muscle and nerve function, blood glucose control and blood pressure. It plays an important role in hydration, muscle relaxation, energy production and, crucially, the deactivation of adrenaline. In addition, magnesium plays a role in the transport of calcium and potassium across cell membranes, which is imperative in nerve impulse conduction, muscle contraction and normal heart conduction.

What are the symptoms of low magnesium?

Deficiency of magnesium can cause a variety of health issues. Early signs may include loss of appetite, nausea, vomiting, fatigue or weakness. As hypomagnesemia (low magnesium levels in the blood) worsens, signs include numbness, tingling, muscle twitching, cramps and muscle soreness. More serious symptoms include abnormal heart rhythms, coronary spasms (remember, the heart is a muscle) and seizures. Magnesium has a direct effect on calcium and potassium levels, so people who take magnesium should have these electrolytes monitored by a healthcare provider through blood testing.

Low magnesium can result from a variety of causes, including chronic diseases, medication use, poor nutrition, lifestyle choices and pregnancy. Older adults are at added risk because of decreased absorption of magnesium with age and renal insufficiency.

How does magnesium affect sleep?

Magnesium is essential for every stage of sleep because of its neuroprotective effect of slowing the metabolic process, lowering brain temperature, and regulating hormones responsible for sleep onset. Magnesium is also known to cause muscular relaxation, which may help with falling asleep.

There are two hormones that are affected by magnesium levels: cortisol (known as the stress hormone) and melatonin (which helps regulate sleep patterns). Magnesium has been reported to decrease cortisol, thereby promoting relaxation and sleep. Magnesium is vital for the function of gamma aminobutyric acid (GABA) receptors in the brain, which initiate sleep. Sufficient magnesium is required to regulate all hormones in the body. With age, the natural decline of these hormones worsens if there is not enough magnesium.

Where can I find magnesium?

You can find magnesium in foods, some bottled water, dietary supplements and medications (antacids and laxatives). Green leafy vegetables, cereals and fortified foods are good sources of magnesium. Foods containing fiber usually have some magnesium. Keep in mind that food processing removes magnesium.

Norma G. Cuellar, PhD, RN, FAAN
Professor, Capstone College of Nursing, University of Alabama

Many foods drain the body of magnesium and should be avoided, especially by people who have low magnesium levels. These foods include carbonated beverages, sugar, high-carb foods, caffeine and alcohol. Also, some medications will deplete the body of magnesium including diuretics, cardiac medications, asthma medications, birth control medications and estrogen. Calcium and magnesium have an inverse relationship, so if you take calcium supplements, then your magnesium level could be low.

An interesting study was published in 2015 on balneotherapy in older adults. Balneotherapy is the use of mineral water baths to improve health and is usually practiced at spas. After a 12-day balneotherapy program, 52 older adults from Spain showed significant improvement in sleep, mood and depression. The water at Balneario San Andrés was hypothermic (at or above 20 C, or 60 F) hard water of medium mineralization with bicarbonate, sulfate, sodium and magnesium as the dominant ions (Latorre-Román et al., 2015).

How much magnesium should I take?

The recommended dietary allowance (RDA) for magnesium varies by age. Dosing also depends on gender and whether a person is pregnant or breastfeeding. For adults, 400 mg daily is usually safe. If you are using magnesium to help with sleep, you may want to take this before bedtime. For some people, magnesium may be stimulating rather than calming. In this case, you should take magnesium in the morning.

Magnesium can be purchased over the counter. Make sure your healthcare provider knows you are taking magnesium, as it may affect other medications you take. If you take magnesium supplements, you should have your magnesium level checked routinely through blood tests. Magnesium can have significant impact on health outcomes and should be carefully monitored.

References

Latorre-Román PÁ, Rentero-Blanco M, Laredo-Aguilera JA, García-Pinillos F. 2015. "Effect of a 12-day balneotherapy programme on pain, mood, sleep, and depression in healthy elderly people." *Psychogeriatrics* (15): 14–19.

Magnesium Fact Sheet: ods.od.nih.gov/factsheets/Magnesium-Consumer

Foundation Certifies Three RLS Quality Care Centers

RLS Quality Care Centers serve as destinations for anyone with RLS who needs expert care, as well as resources for regional providers and support groups.

To achieve certification, providers must meet rigorous criteria for treating patients with a range of RLS complexity and comorbidities. Each center must provide ongoing treatment to at least 200 patients with RLS, and each certified specialist must manage at least 50 RLS patients. Centers are also required to demonstrate that they have managed at least six patients with multiple co-existing medical conditions and/or medication management issues related to RLS.

Visit www.rls.org/treatment/quality-care-centers to learn more about RLS Quality Care Centers.

Scripps Clinic Viterbi Family Sleep Center
10666 North Torrey Pines Rd. La Jolla CA 92037
858-554-8845
www.scripps.org/medical-groups/scripps-clinic/services/sleep-medicine

Certified healthcare providers:
J. Steven Poceta, MD (Director)
Lawrence Edward Kline, MD
John W. Cronin, MD

"At Scripps Clinic, we are honored to be recognized as an RLS Quality Care Center. This designation is not about us, however – it is about increasing awareness of RLS for people who are undiagnosed and about trying to improve the lives of patients who have RLS. We hope that this RLS Quality Care Center designation is the beginning of more research and better treatment of patients."

– J. Steven Poceta, MD
Director of the RLS Quality Care Center at Scripps

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www.eoc.ch/Centri-specialistici/Neurocentro-della-Svizzera-Italiana/Neurologia/Centro-sonno-ed-epilessia

Certified healthcare providers:
Mauro Manconi, MD, PhD (Director)
Sylvia Miano, MD, PhD
Stephany Fulda, PhD
Pietro-Luca Ratti, MD, PhD

"As the second RLS Quality Care Center based in Europe, improved quality and accessibility to expert care will result in improved quality of life for RLS patients living in the European Community."

– Mauro Manconi, MD, PhD
Director of the RLS Quality Care Center in Lugano, Switzerland

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Certified healthcare providers:
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Kanika Bagai, MSCI, MD
Jennifer Hensley, EdD, CNM, WHNP, LCCE
Beth Ann Malow, MS, MD
Athlea Robinson-Shelton, MD
Raghu Pishka Upender, MD

"We are pleased that Vanderbilt University Medical Center has been certified as a Quality Care Center for the treatment of RLS. We appreciate very much this honor and will do our best to live up to this distinction and provide adults, children and adolescents with the very best care possible."

– Dr. Arthur S. Walters
Director of the RLS Quality Care Center at Vanderbilt

Augmentation Video Highlights Common Drug Side Effect

The RLS Foundation wants every person who has RLS to know about augmentation, a serious side effect of some dopamine medications.

In February, the Foundation published the video *RLS and Augmentation*, available on the Foundation's YouTube channel. The 20-minute video includes personal accounts by patients and interviews with medical experts at certified RLS Quality Care Centers.

For example, Foundation member and volunteer Donnie Kee controlled his RLS symptoms for 15 years by taking a dopamine medication. This changed suddenly one day, says Kee, when "the RLS just went into overdrive." His symptoms started happening earlier in the day and became so severe that he couldn't function at his job.

Kee was experiencing augmentation, a serious but reversible drug side effect. RLS Foundation Executive Director Karla Dzienkowski says, "Physicians who treat RLS patients need to screen for augmentation at every office visit. Patients need to be watchful for symptoms happening earlier in the day. This is a serious problem that needs to be addressed. RLS patients need to know that augmentation is treatable and manageable."

Describing the indescribable

Describing RLS – the disease itself – can be difficult. In *RLS and Augmentation*, RLS Foundation Board Member Starla Phelps says, "You can't. When you say, well it's kind of like you've got worms crawling inside your legs or your arms, they just look at you. And that isn't an adequate description. I can't tell you what it's like – electricity, worms, feeling like you've got to get out of your body."

Patients give powerful accounts of how RLS interferes with daily life – for example, not being able to sit still in public places, hold a pen, or get a good night's sleep. Foundation member Peter Brooks says his RLS symptoms began when he was 48 and forced him to retire at age 50. "When I first started experiencing them, they caused sleep deprivation, and that led to depression and despair because the symptoms just wouldn't stop," he says.

Medical experts at RLS Quality Care Centers discuss RLS prevalence and demographics, as well as medications available to relieve symptoms. According to Dr. William Ondo (Houston Methodist Neurological Institute), there is no universal solution for RLS – treatment must be tailored for each individual. In the case of dopamine agonists, which can lead to augmentation, he says that treatment is "a double-edged sword."

Dr. Christopher J. Earley (Johns Hopkins Center for Restless Legs Syndrome) explains that the term *augmentation* was coined to distinguish the phenomenon from a simple tolerance. "If the disease is progressing and they are on a dopamine agent, then the probability is that it is not the disease; it is the symptoms being driven by the drug itself," he says. Augmentation can be reversed by discontinuing the medication.

Withdrawal can cause intense symptoms, however. For Kee, it was the 34 worst days of his life, but he endured and has found relief in a different class of medication. He now volunteers as a support group leader for the RLS Foundation.

"I've been through it long enough that I pretty well understand the cycle and when people get into [this] serious condition," says Kee. "…I try to be their friend and their hope."

The video received close to 4,000 views within one month of posting on YouTube, generating many positive comments and an uptick in membership for the RLS Foundation.

In the words of one Foundation member, "Thank you for this video, a very helpful explanation for others who do not have RLS. It is so hard to describe!"

A broader augmentation awareness campaign

The *RLS and Augmentation* video is part of a broader strategy to inform patients, healthcare providers and the public about augmentation. In January, the Foundation distributed a "meeting in a box" for support group leaders to share the video and additional materials in their communities.

In April, the Foundation distributed the white paper "Summary of Recommendations for the Prevention and Treatment of RLS/WED Augmentation" to over 45,000 physicians across the U.S. in a direct mail campaign. The paper was published by a joint task force (the International Restless Legs Syndrome Study Group, the European Restless Legs Syndrome Study Group, and the RLS Foundation, 2015).

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Board of Directors

Thank you for your continued financial support and unwavering commitment to the RLS Foundation during our 2016 fiscal year. This year, individual donors provided the majority of support for Foundation programs and activities, representing over 75 percent of donations collected.

Our popular monthly webinar series, support group meetings and educational materials serve to educate the general public and medical community about RLS. In fact, in early 2016 the Foundation distributed an important research paper summary on the prevention and treatment of RLS augmentation to 45,000 medical practitioners around the United States. Additionally, we updated our website, providing easier and more user-friendly access to Foundation resources. Our social media presence has grown exponentially, and our active platforms now include Facebook, Twitter, Instagram, YouTube, LinkedIn and Google+. This has allowed us to expand our reach and fulfill our mission to bring greater RLS education and awareness to the public.

Furthermore, this year we reinvigorated our Research Grant Program by offering up to eight new pilot grants totaling $200,000. The addition of three new Quality Care Centers provided individuals living with RLS access to care from leading RLS experts. Together, these two robust programs fulfill our Foundation goal of finding better treatments, and ultimately a cure for RLS.

The RLS Foundation's Finance and Audit Committee monitors revenue and expenditures to ensure they are in balance, and reviews forecasts for the upcoming fiscal year. Meanwhile, the Board of Directors provides financial oversight for the organization by ensuring monies are spent in programs beneficial to the members of the RLS community.

Each gift received, regardless of size, allows us to fulfill our mission and ultimately, brings us one step closer to a cure.

Sincerely

Lewis M. Phelps
Chair and Acting Treasurer, RLS Foundation Board of Directors

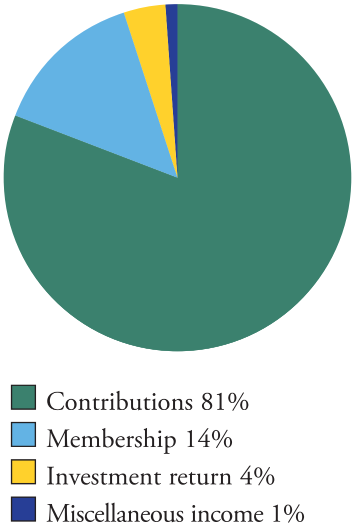
Restless Legs Syndrome Foundation

Statements of Activities • For the Fiscal Year Ended September 30, 2016

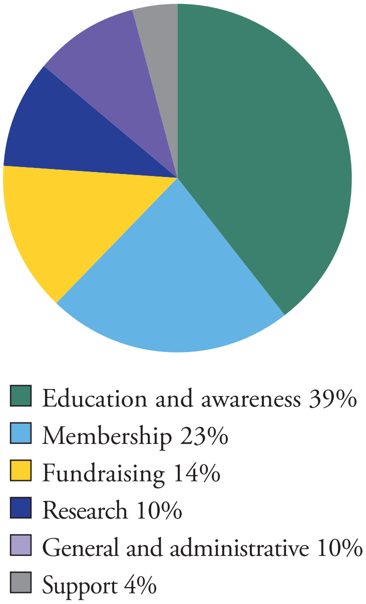
Revenues and support	**2016**
Contributions	$ 650,241
Membership dues	110,428
Investment earnings	31,785
Other	139
Total revenues and support	$ 792,593
Expenses	
Program services:	
Education	$ 325,222
Membership	189,605
Research	79,882
Support groups	31,104
Total program services	625,813
Fundraising	117,390
Management and general	81,002
Total expenses	824,205

The RLS Foundation's full financial statements, the complete audit opinion of Reynolds and Franke, and all accompanying notes are available online at: www.rls.org

Where Our Funds Come From



Where We Use Our Funds



RLS
RESTLESS LEGS
SYNDROME
FOUNDATION

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2016

LASER FOCUSED TO FIND A CURE